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ABSTRACT

To illustrate the principles and conflicts inherent in ensuring the self-determination of individuals with disabilities, this paper discusses the challenges faced by the parents of Shari, an adult with developmental disabilities. Throughout Sheri's 30 years, her parents have sought to create the kind of supports and opportunities that will put Sheri in control of her life on a day-to-day, hour-by-hour basis so that she can live up to her responsibilities as a family member, as a neighbor, and as a citizen. For four years Sheri has rented a home in a quiet Seattle neighborhood. She shares her home with two tenants who exchange a reduction in their rent for assuming responsibility for Sheri's safety overnight. She has expanded and strengthened her circle of support and expanded the number and variety of local places and activities familiar to her. In the past 3 years, she has developed a strong and effective personal assistance team in collaboration with two service providers. This paper explores the limits of self-determination, the influence of parent advocacy, community supports that have enabled Sheri to remain independent, her personalized service design, conflicts that arose between the parents and agency staff, and the resolution of differences. (CR)

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WALKING TOWARD FREEDOM: ONE FAMILY'S JOURNEY INTO SELF-DETERMINATION

by
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1999

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Walking Toward Freedom

One Family's Journey Into Self-Determination

John O'Brien and Connie Lyle O'Brien

The disposition of [hu]mankind, whether as rulers or as fellow citizens, to impose their own opinions and inclinations as a rule of conduct on others is so energetically supported by some of the best and by some of the worst feelings incident to human nature that it is hardly ever kept under restraint by anything but want of power; and, ...unless a strong barrier of moral conviction can be raised against the mischief, we must expect, in the present circumstances of the world, to see it increase.

— J. S. Mill, *On Liberty*

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[1] Our visits to learn from Sheri and her family and circle were sponsored by the Center for Community Support: A Project of TASH in Seattle Washington.

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[2] J.S. Mill (1859/1997). *On liberty.* New York: Norton Critical editions. P. 52 The quotations from Mill below are from page 48.

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Introductions

The reason to reform services in line with the principles of self-determination is to increase the control people with developmental disabilities have over the conduct of their own lives, to remove the power that service systems have to dictate such fundamental matters as where and with whom they live and who assists them, and consequently to decrease the opportunity that service workers have to rule over those they assist by imposing their opinions and inclinations as a rule of conduct. Such control of everyday circumstances provides a foundation for people exercising the rights and fulfilling the responsibilities of citizenship.[3] However, as we will see, the ability to choose who assists a person and to specify the terms of that assistance does not replace a thoughtful search for the moral conviction necessary to steer the relationship between people and their assistants.

Sheri in April 2000

Sheri and her parents, Marge and Earl, are among the pioneers of self-determination, though they have not participated in any service system reform project by that name. Throughout Sheri's 30 years, they have dedicated much time and energy to stretching available resources to fit Sheri's life and resisting pressure to fit Sheri to what the service system has available. They aim to create the kind of supports and opportunities that will put Sheri in control of her life on a day-to-day, hour-by-hour basis so that she can live up to her responsibilities as a family member, as a neighbor, and as a citizen. Marge and Earl and Sheri's commitment to one another has attracted allies who have supported the three of them through the past nine years of their journey toward self-determination.

Their work has born much fruit. For four years Sheri has rented a comfortable home in a quiet Seattle neighborhood. She shares her home with two tenants who exchange a reduction in their rent for assuming responsibility for Sheri's safety overnight. She has expanded and strengthened her circle of support and, despite recurrent health setbacks, slowly and steadily expanded the number and variety of local places and activities familiar to her. In the past three years, she and her circle have developed a strong and effective personal assistance team in collaboration with two service providers: GRO, a local residential service provider which has expanded its mission to partner with Sheri and other people with disabilities who want to take responsibility for directing their own services, and Highline Community College, a provider of community experience services. Sheri's hospitality instructs a steady stream of visitors interested in innovative forms of support and influences the family members of other people with substantial disabilities, service system administrators, and elected officials.

[3] For a manifesto that asserts this point and identifies its implications, see *The Seattle 2000 Declaration on Self-Determination and Individualized Funding.* (http://members.home.net/directfunding/Declaration.htm)

Marge and Earl's success in significantly decreasing the service system's power to dictate their daughter's living conditions teaches the importance and the difficulty of upholding a barrier of moral conviction against the all too human tendency to impose on others' liberty. Indeed, this family's contest with able and concerned service workers over who was imposing and what barriers to erect against imposition nearly wrecked their experiment in self determination less than a year after the family gained the ability to direct service system funds to a service provider of their choice and thus to implement a tailor-made support system that established their daughter in a home of her own.

Every stage and level of Sheri and Marge and Earl's journey demonstrates the reality that self-determination is a matter of continually forming, extending, repairing, and sometimes ending relationships. Their experience confronts the idea that self-determination is a matter of sovereign individual consumers issuing orders and dictating terms to subordinate providers. Marge and Earl have advocated vigorously, negotiated skillfully, and asserted their views persistently in order to establish their authority to define Sheri's living conditions based on their understanding of who Sheri is and what matters to her. The energy and information necessary to establish their authority comes from their relationship with each other and their connection with their circle of support. The state of relationships with the staff team that assists Sheri daily can either facilitate or frustrate their authority. For Sheri, self-determination is about relationships or it is about nothing but words.

Marge and Earl want to repay their opportunity to make flexible use of service system resources by sharing their learning. They tell their story forthrightly to anyone who cares to know what they have discovered about themselves on their journey toward self-determination. As part of this effort, they have invited us twice to visit and listen to their story from their point of view and from the many points of view represented by the people involved with them. This we have done gladly. They have also given us permission to add our own reflections on what we have seen and heard. For this we are grateful.

In what follows, we consider what this family's story tells us about the practical consequences of different ways of understanding the "self" in self-determination. It must be clear that this is our way of exploring Sheri and Marge and Earl's story. Along their way, we hear them living out a relational understanding of self, an understanding that generates dilemmas for them and creates conflicts with people who understand self in individualistic terms. While they don't find anything objectionable in our interpretation of their story, Sheri, Marge and Earl did not set out to investigate different models of self, they set out on a journey to do what they believe is right.

Where are the limits of self-determination?

Those looking for a limit to the principles of self-determination might think of someone like Sheri. Sheri is deaf and blind; she experiences a poorly controlled seizure disorder; consequent to stroke she has significant mobility impairments; and she requires very substantial assistance to learn. Sheri uses a few manual signs and some objects to signal her immediate interests, but mostly expresses herself through body movement and vocalization. As far as anyone has understood her up to now, Sheri's communication comments on the present and the immediate future, as when she takes the car keys from their hook to indicate her desire to take a ride or vocalizes to express discomfort or anger.

How can Sheri exercise self-determination beyond asking for the help she needs to go for a walk or a ride? For many people, the common sense of the matter plainly shows she cannot. Even J.S. Mill, who argued with an eloquent force "that the only purpose for which power can be rightfully exercised over any member of a civilized community … is to prevent harm to others", made an exception that seems custom-made to describe Sheri: "… this doctrine is meant to apply only to human beings in the maturity of their faculties…Those who are still in a state to require being taken care of by others, must be protected against their own actions as well as against external injury."

Sheri's legal status ratifies the need for others to take care of her. Her parents, Marge and Earl, hold guardianship of Sheri's person and property. So Sheri can not decide, for herself alone, where and with whom she will live and who will assist her. Again, the common sense of the matter seems clear to most people. Sheri's guardians control her circumstances in light of their understanding of her best interests. As they see it, it is a fiction to speak of Sheri as being or becoming self-determining.[4]

So it may be. But if it is a fiction, it is an interesting and powerful one that has strongly influenced Sheri's life for the better. Her mother, Marge, says that she has always acted on the belief that Sheri has far more capacity than others, *including Marge herself*, can see. Marge understands her guardianship not so much as making substitute choices that remedy Sheri's incompetence than she understands being a guardian as finding ways to actively represent Sheri's potential to know and to do and to control more than anyone, including Marge, now thinks she can. What Marge believes to be in Sheri's best interests are opportunities and supports that will

[4] This position has merit when assigning headings to service system reforms. We prefer the British heading of "direct payments" or the Canadian heading "individualized funding" as a more accurate way to identify reforms that put public funds for disability services under the direct control of people with disabilities or their families to the usage that calls such bureaucratic changes "self-determination", thus confusing what systems do –providing controllable individual budgets- with what people do –figure out how to live lives that make sense to them. However, we think that self-determination does make an accurate heading for Sheri and Marge and Earl's journey together. The service system's capacity to develop an individual contract for her residential assistance has been an important help on their way.

challenge Sheri herself and those around her to find out through action who Sheri is and what her gifts to others are.

Earl, Marge, and Sheri

Earl complements Marge's relationship with Sheri. His deep love and affection for Sheri just as she is on any given day shapes his habit whenever he visits Sheri's house or meets her outside. Earl's first move is to the side on which both Sheri's sight and her arm movement is least impaired and his first words are to ask her to hug him. His pleasure when she reaches to hug him, as she almost always does, lights the space around him. Retirement has given Earl more time to spend with Sheri, with his other four children and his grandchildren, and with his church, though his plans for extended travels with Marge have been curtailed by his sense of what Sheri needs from him now. Earl generally plays a stabilizing and supportive part in Marge's efforts to make things work for Sheri, though he meets any threats to Sheri's well being assertively.

The path of Sheri and Marge and Earl's journey allows consideration of the most useful way to think about the "self" in self-determination.[5] From the point of view of those who understand "self" as the source of autonomous choices within an individual who marshals her resources to take independent action and deal with the consequences, Sheri doesn't have much of a self. She is determined by other selves, who are independent as she is not. Their task is to keep her safe and healthy and perhaps to try to teach her to someday become an independent self. If her parents do not do the work of taking care of her themselves, their responsibility to Sheri is to find an agency they can trust to keep her safe and healthy and to exercise their powers of guardianship to assure that service providers live up to their end of the bargain.

From the point of view of those who understand "self" relationally, as the capacity to discover and contribute to activities of mutual interest to a person and those she cares about, Sheri fully inhabits a self. Her continuing reliance on others for a level of decision making and assistance that most people grow out of as they grow up, makes her self-as-relational more obvious and present than it is for most adults in North America. Here, at least in Sheri's culture, the ideal of individual, even isolated, autonomy determines many people's understanding of self and makes them react to dependency on others as though it were a sign of immaturity or shameful weakness. The sense of self shrinks when need for others shows. Her obvious relatedness –for instance, Sheri does not eat without assistance and is often most comfortable in public presentations if she has very close physical contact with someone she knows– would be a stumbling block if Marge and Earl saw her dependency as a shameful matter, best veiled in privacy. However, because of their own delight in her and because they see Sheri's dependency as a shared matter, which imposes an obligation on Sheri to do as much as she can and otherwise as rightfully belonging to the people around her,

[5]We are indebted to Peter Suber (1992) *Self determination and self-hood*. The Emerson Lecture, Earlham College. for his discussion of the implications of these contrasting understanding of self to self-determination. www.earlham.edu/~peters/writing/emerson.htm

they have set shame aside in favor of reaching out to engage others in their lives. These others hold a part of Sheri's self. The state of their relationships determines her level of self-determination: when Sheri and her allies and assistants can function in harmony her life follows her own path; when they are out of joint with one another her life is determined by others.

This diagram suggests a portrait of Sheri's relational self as it looked to people in her circle in Spring 2000. The state of these people's relationships with Sheri and the state of their relationships with each other determine how free she can be to meet her responsibilities and enjoy exchange of the gifts of friendship and citizenship.

The desire to come to know Sheri better and to support Sheri to come to know herself better motivates Marge and Earl and Sheri, with the help of a circle of support, to take the question of what self-determination might mean for Sheri as the invitation to walk on a journey together. Sheri enjoys walking, especially when there are interesting grades, surfaces, textures, smells, and breezes to experience and someone she likes providing the close physical support she needs to take each next step. Though she walks slowly and deliberately, she sets a pace with which prevailing ways of providing services find it very difficult to keep up.

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The sections that follows will sketch their journey so far, explore the conflicting mindsets that nearly wrecked their efforts, and describe how they have developed a way to keep on walking together.

Steps along the way

Marge's belief in Sheri's unknown capacity leads her to seek new ways to understand and respond to Sheri's multiple disabilities. Sometimes Marge's search has taken her to learn from widely recognized experts, such as those at the Helen Keller Center. Sometimes her search has taken her to alternative medicine and the healing resources of her faith. Often, expressing the independent perspective on Sheri's disabilities shaped by her search brings Marge into conflict with people who have lower expectations for Sheri or people who have different views of where to turn for help.

Marge is acutely interested in the interactions among Sheri's impairments and their connection both to Sheri's general physical well being and to the state of the relationships people have with Sheri and one another. The Sheri that specialists see is different from the Sheri that Marge sees. Specialists see particular conditions: seizures or sensory impairments, or behavioral challenges, or problems with movement. Marge sees the "ands". Sheri is a person and she has sensory impairments and seizures and post-stroke movement difficulties as well as recurrent breathing and bowel problems that seem to both express and exacerbate the other conditions. And the well-being of the person Marge understands as "the whole Sheri" seems to her to be strongly influenced by the level of unresolved conflict among people who are important to Sheri.

Marge is open to disagreement and correction as long as others deal with these conflicts in ways that show Marge that they respect her position in Sheri's life, are willing to consider new ideas, and, most important, that they seek a deeper understanding of Sheri. When experts and service providers have not lived-up to this standard, Marge and Sheri and Earl have moved on, often leaving those who have failed Sheri with stories to tell about "mothers from hell" and the fathers who fail to rein them in.

When persuasion and due process failed to convince their school system to implement a suitably intensive communication program for Sheri, Marge and Sheri moved to an apartment in a more accommodating school district where they lived until she graduated.

Marge and Sheri

As school graduation approached and Marge learned of resource limitations in the adult services system she says she became "one of the squeekiest wheels on the planet." She engaged system administrators and legislators in an effort to expand the state resources available for family support and for residential services. When funding became

available to support some residential places for people who would otherwise be eligible for nursing home placement, Sheri moved into a community residential service program, which in Washington State is called "Intensive Tenant Support (ITS)".

Sheri's time in this program, and in a second ITS program to which she transferred after the first program proved unwilling to recognize Marge and Earl's place in Sheri's life, was critical to the journey toward self-determination in two ways. First, it helped Marge and Earl to recognize the ways in which even very small group living disadvantaged Sheri and to conclude that she needed a service design personalized for her. Second, it gave Marge and Earl some free time in which they could rest, explore new possibilities, and carefully lay the foundation for an approach that would much better fit Sheri.

In exploring possibilities, Marge made the most of available opportunities to learn. A federally funded project on Transition and Individual Futures Planning for people with developmental disabilities and deaf-blindness[6] confirmed the importance of a positive future vision as the context for the kinds of specialized support that could continue to improve Sheri's communication and skills and encouraged the formation of Sheri's circle of support. Washington State's Residential Technical Assistance Project brought Marge and Earl together with people from Midland, Michigan who offered practical examples of circles of support working to develop personalized housing and support options that included a role for community renters, who share rent and household expenses and provide some people with a back-up in case they need help overnight.[7] A circle of support and a personal futures planning process provided a way to shape these new ideas to the realities of Sheri's life in Seattle.

Even more important than the information Marge has gathered have been the alliances she and Sheri and Earl have made through participation in projects and conferences.

Marge tests the professionals in Sheri's life. She tests by proposing a new way to assist Sheri and grades based on the professional's willingness to accept her as a valid source of information and to do what they can to support the new approach. Extra credit goes to those who add new information to one of the ideas she brings to create an opportunity for Sheri that she had not imagined. Marge's tests challenge a common division of authority between parent and professional because she gathers information in expert territory and makes judgements about its use that many professionals view as reserved for them. As one professional who withdrew from serving Sheri put it, "It is always hard to deal with moms who want to be involved, but Marge acts like more than a mom, she acts like an expert. It's just about impossible to work with parents who won't respect boundaries." Marge recognizes that acting like "more than a mom" can stress service workers, but those who pass her test earn both her respect and the right to influence her thinking.

[6] N. Haring and L. Romer (1994). Welcoming students who are deal-blind into typical classrooms. Baltimore: Paul Brookes.

[7] The ARC of Midland. *Supported community living: The Midland experience*. Video. Midland, Mi. The ARC of Midland. www.thearcofmidland.org

Though many professionals have refused to see Marge as a source of credible ideas for assisting Sheri, some have come through with flying colors and become valued members of Sheri's circle of support, a group whose gatekeeping belongs to Marge and Earl. Nancy, the teacher Marge sees as contributing the most to Sheri's growth during her school years, remains a valued adviser and supporter. So do Karen, who directs the community experience program that has served Sheri since her final years of school, Duane, who directs the agency that administers Sheri's residential services contact, Mary who directs the state's Residential Technical Assistance Project, and Linda, who leads Sheri's staff team. Distinctions between paid and unpaid people or professionals and family members matter much less to Sheri and Marge and Earl than the distinction between those who box Sheri into one of their categories and those who demonstrate persistence in understanding Sheri's dream and assisting her to pursue it.

Mary has done many of the tasks that self-determination demonstration projects call "service brokerage" or "support coordination" as an expression of her interest in action-research that demonstrates new possibilities in community building and personalized support. She has assisted Marge and Earl with planning and problem solving, linked them to resource people, supported them in their negotiations with the regional office that contracts for Sheri's services, helped with their search for suitable providers, and encouraged them to draw on the connections and opportunities naturally available to them in their own lives and in Sheri's neighborhood. These tasks are manageable within the time Mary can give because Marge and Earl have energy, time, and skill to invest in making things work for Sheri. Over time, Mary has earned Marge and Earl and Sheri's trust by keeping agreements around particular tasks, saying no when she doesn't have the time to meet a particular request, honestly sharing her thoughts and reactions, accepting and supporting Marge and Earl's decisions even after she has expressed her own reservations, and, most important, honoring and enjoying her own participation in Sheri and Marge and Earl's family relationship.

The combination of Sheri's insistent call for better living arrangements, Marge's skill as an advocate, Mary's knowledge of the service system, and the Regional DDD staff's interest in exploring new forms of support led the region to develop a residential services contract for one person, Sheri.

Piece-by-piece Marge and Earl and Sheri's circle of support assembled all but one of the elements that have come to define self-determination as an administrative reform. These elements were not available preconditions for their journey, the circle grew to include people who worked to create them as their walking together revealed new problems and new information. They did not set out to implement self-determination as it was defined by the Self-determination Projects sponsored by the Robert Wood Johnson Foundation (RWJ)[8], they solved the problems that came up in Sheri's journey

[8] C. Mosley and T. Nerney (July, 2000). Emerging best practice in self-determination. *Common Sense*. See the RWJ Self-determination project website at www.selfdetermination.org

in the best way they could. Sheri's arrangements can be translated into the vocabulary of the RWJ projects:, by 1995 Sheri had an individual budget, an independent broker, a personal futures plan that clearly specified what assistance is essential to her and supported continuing problem solving, and a circle of support to orchestrate the combination of paid and unpaid assistance available to her.

One element specified by the RWJ project design is missing. Sheri does not use a fiscal intermediary –an agent independent of the state authority that receives and disburses a person's funds at the person's direction. The Regional DDD office administers her residential services contract and assigns Sheri a case manager to assure that her needs are met according to their contract with the service provider the regional office selects cooperatively with Marge and Earl. Even if more direct control of funds were available to Sheri, Marge and Earl say they would choose to leave contract administration with DDD and use a service provider of the family's choice to hire staff. This means that Sheri's arrangement depends on the continuing willingness of the regional office to contract for Sheri as an individual and to allow Sheri and Marge and Earl to choose Sheri's provider with the assistance of Sheri's case manager. Though the regional office remains supportive, the lack of a structure to assure individual control could threaten the stability of Sheri's living arrangements. However, the only real threat so far came not from the bureaucracy but from conflict between Marge and Earl and an agency and staff hired with their active participation.

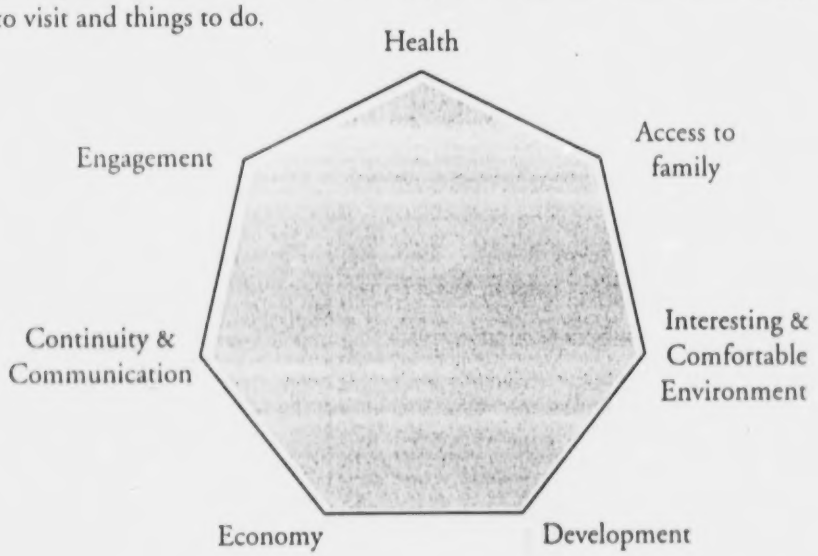
In 1996, Sheri moved into the home where she still lives. The design for her services has proven robust and effective, even as Sheri has weathered crises in her health and great difficulties among the people who assist her. The greatest threat to the security of her home in the past four years came from a conflict that split Sheri's family and most of her circle of support from the staff team that assisted her day-to-day. Both Sheri's personalized service design and the conflict that nearly ruined it highlight the fundamental importance of relationships to self-determination.

A personalized service design

For some people with developmental disabilities it may be enough to simply be able to pick and pay the service provider whose existing offering best matches their specifications. For Sheri, this has not worked. Before the development of her current arrangements, two competent and well-respected residential support providers were unable to assist her adequately within the elements of their Intensive Tenant Support programs specialized for people with dual sensory impairments.

Sheri succeeds today because she has more than an individualized plan on paper, she has a personalized program design in practice. This program design fits what the people who care about her most and know her best understand as essential to her well-being and development.

- Sheri needs direct assistance to engage in most activities other than the rhythmic tapping of hard objects on hard surfaces, and several years of experience in highly staffed programs with even one or two other people with disabilities has shown that it doesn't work for her to compete for assistance. To assure engagement, her personal program design calls for her to have assistants who have sole responsibility to her and for her to be the only person who needs personal assistance living in her home.
- Sheri has a number of continuing and interacting health problems and her limits in communication can make it difficult to understand when and how she is uncomfortable or ill. Marge takes a particular interest in the ways that Sheri's difficulties interact and Sheri uses alternative healthcare treatments to strengthen her whole system. To assure the best possible health, Sheri needs the people around her to implement her daily health care regimen, carefully monitor her situation and call for help when she seems in distress, and faithfully record information that helps Marge collaborate with a variety of healthcare professionals to make good judgements.
- Sheri requires extensive personal assistance and it takes new assistants time to learn the body language through which she relates. To assure continuity, her personal program design calls for paying staff a fair and competitive wage and budgeting for time for staff to learn how to understand Sheri alongside people who know her.
- Space to move around and experience different indoor and outdoor environments matters to Sheri, as does sufficient distance from neighbors to minimize disturbance when she expresses discomfort or dissatisfaction with extended periods of loud vocalizing that can last into the night. To assure an interesting and comfortable environment, her personal program design calls for a detached house with a yard on a quiet street with sidewalks in a neighborhood that offers interesting places to visit and things to do.



- Access to her parents matters to Sheri. To assure family connection, her personal program design calls for a location convenient to her parent's home.
- Sheri shows the potential to continue to develop her physical, sensory, and communication abilities. To assure her development, Sheri needs assistants who will offer her real choices, organize her partial participation in routines, and assist her in her daily sequence of structured developmental activities.
- To keep Sheri from demanding more than a fair share of funds from a system strained by chronic under-funding, her individual program design assumes that the developmental disabilities service system will not have to invest more in Sheri's living in her own home than they would expend to support her in the community residential program from which she moved. To assure economy, her personal program design calls for Sheri to share her home with two community renters who share household expenses and sublet from Sheri at a somewhat reduced rent in exchange for seeing to Sheri's safety overnight. They accept the obligation to make a first response to any difficulty Sheri might have in the night and to notify the person who is on-call for Sheri. When Sheri's health requires overnight assistance, family and staff provide it.

Assuring that Sheri has the assistance that she needs to stay active and to deal with recurrent health problems can stretch the commitment of all those involved with day-to-day assistance. Sheri's budget for residential support and her share of funds for her community experience program currently provide her with the equivalent of 2.85 full time staff. This provides Sheri with one-to-one staff from 7 am to 10 pm, seven days a week.

Marge and Earl are the primary underwriters of any gaps in Sheri's assistance, coming in when Sheri needs overnight assistance and covering some staff illnesses or absences and some staff vacation time. They deal with Sheri's finances and the household bills and take care of her medical appointments. They also do routine home and yard maintenance, a contribution much appreciated by Sheri's landlord, who is also her across-the-street neighbor. This high level of parental time investment provides Sheri with support staff who can focus their full attention on supporting her engagement and participation in household routines and community life. It also sets the stage for conflict. Whether this conflict undermines Sheri's security, as it did in the first year of her life in her own home or enriches her well-being, as it has in the past three years, depends on the quality of the relationships among the people Sheri counts on.

Almost losing the way

About a year after Sheri moved into her own home, the service provider Marge and Earl selected to assist Sheri at home gave notice of their decision to withdraw from the contract to serve Sheri. We interviewed almost all of the people involved just after the agency gave notice and before her contract was taken up by the provider who continues to support her today. We constructed the following understanding of the conflict that led to this change based on what we heard; participants will have their own understandings, which may be very different from ours.

Most discussions of self-determination seem to assume that given the opportunity to direct individual budgets, consumers will fire unsuitable service providers. Sheri's situation reminds that contracts work two ways. In this case, the service provider exercised the option to fire Marge and Earl, though agency managers very much regretted losing the opportunity to assist Sheri. Though the ending was difficult on all sides, the agency behaved honorably, offering ample notice and collaborating generously in the transition to a new agency. They took the step of withdrawing service because they believed that current arrangements were unsuited to Sheri's needs and inconsistent with their responsibilities as a service provider.

Because of their commitment to Sheri, the agency proposed two major modifications of Sheri's personalized service design as the basis for negotiating a new contract with them: 1) the two community renters would be replaced by two housemates with developmental disabilities whose funding, pooled with Sheri's, would cover 24 hour staffing for all three residents; and, 2) Marge and Earl would agree to respect the agency's boundaries by scaling back their decision making role to the level typical of other parent guardians involved with the agency and significantly reducing their day-to-day involvement with Sheri.

Though the agency had found their involvement with Marge and Earl extremely trying, there is no reason to doubt the sincerity of their offer. Because they believed that Marge and Earl were irrational where Sheri was concerned, staff had different opinions about how much of the reasoning behind their offer to continue to provide suitably modified services they could openly discuss with Marge and Earl. However the staff who assisted Sheri day-to-day saw at least four ways in which Sheri would benefit from the proposed changes to her service design. She would experience consistent expectations, routines, and programming based on realistic expectations rather than having her day and her regimen interrupted and changed whenever it suited her parents to try out some new idea. She would have staff available 24 hours a day rather than relying on untrained housemates, who had proven difficult to recruit and retain, for overnight help and her parents for back-up. She would be able to establish the distance from her parents necessary for an age-appropriate relationship with them; her mother would no longer be intruding into every detail of her life.

While they thought that Marge would find the separation especially traumatic given what they viewed as her enmeshment in Sheri's life and the unresolved grief and guilt that they believed fuels her inability to accept the extent and the implications of Sheri's disabilities, they thought that, in time, Sheri would have a mom who would let go of her and let both their lives take their separate courses. They also believed that Marge would be psychologically healthier and her relationship with Earl would be better once she had worked through the trauma of letting go of Sheri.

Though they were aware of tension with some staff, Marge and Earl were surprised by the agency's announcement that it was exercising its option to terminate the contract. Marge had spoken her mind whenever she saw a problem or had a suggestion to make things better for Sheri and thought that she had established open communication with staff. When she saw she had offended someone, she apologized and explained the reasoning behind her behavior. What she did not know is that the staff assigned to the house and Sheri's housemates had agreed that they would placate and ignore her. One staff person described the tactic this way, "It doesn't do any good to try and reason with Marge. She is way too emotionally involved with controlling Sheri's life for that. So we just let her say whatever she wants and we nod and say, 'You're right, Marge.' or 'Yes, Marge.' And then we just go on and do what we know is best for Sheri when Marge leaves."

With the circle's support, Marge and Earl considered their options and decided against revising Sheri's personalized service design. With Mary's help, they made contact with Duane, the Director of GRO, and negotiated for GRO to take over Sheri's residential contract. The agency withdrawing from the contract worked hard to assure Sheri a smooth transition and some staff stayed with Sheri for a time under the GRO's contract.

The circle helped Marge and Earl to think about the lessons in this ending. Three changes were made in the administration of Sheri's supports: 1) a subgroup of the circle, including Marge and Earl, took responsibility for week-to-week management; 2) Sheri's service funding was reconfigured so that the management group could treat both residential funds and day service funds as a unified budget; 3) a sub-group of the circle began to explore the incorporation of *Envisage*, a company to manage rent and household expenses for Sheri and her housemates and for other people with disabilities with innovative housing and support arrangements.

As the diagram shows, Sheri depends on a web of relationships for a unified household budget that gives her the financial flexibility necessary to implement her personalized service design. These interagency relationships in turn depend on personal relationships among the people responsible for the different pieces of her financial puzzle. Adopting the systems reforms advocated by the RWJ Self-determination Project would simplify this structure considerably. Under that design,

funds would be unified at the state level, allocated to Sheri through an individual budget, and disbursed by a fiscal intermediary at Sheri's direction to those who provide her services. However desirable these reforms might be in streamlining fund allocation and clarifying Sheri and Marge and Earl's responsibility to act as informed buyers of services, they would not dissolve the need for effective collaboration among the people who constitute Sheri's relational self.

The growth of irreconcilable stories

It is obvious to say that this ending resulted from communication problems. What is interesting is to consider the sources of these problems in the different ways of understanding that divided staff from Marge and Earl. In this instance, better communication could not simply mean more talk or even more honest talk. The more people talked the more divisive their differences grew over the role of the service agency and its staff in relationship to family and circle members.

As we listened to agency staff and circle members reflect on the agency's decision to withdraw, it seemed to us that the network of individuals and groups around Sheri had locked into opposing positions on almost every dimension of their shared situation. These oppositions developed for at least five interlocking reasons:

- Sheri's voice always depends completely on other's interpretations of her behavior and situation. Her signals, while sometimes strong, are fundamentally ambiguous. In the same situation, her vocalizing was interpreted by one group as a sign of physical discomfort and by another group as an expression of anger at her mother.
- People on both sides felt strong concern for Sheri and strongly believed that they understood Sheri's needs and potentials best.
- People on each side saw the other side's claim on knowing what was best for Sheri as invalid. From the staff's point of view, Marge and Earl were too emotionally enmeshed to see Sheri clearly. From Marge and Earl's point of view, staff may have had professional knowledge about Sheri's sensory impairments or difficulties in learning but they lacked familiarity with "the whole Sheri" and seemed tone deaf to the music of Sheri's dreams.
- The actors in Sheri's world are not only individuals, but members of groups. As the conflict grew, staff and housemates formed one group based on a feeling of closeness to Sheri that was strengthened by their belief that Marge was over-involved in Sheri's life in a destructive way. This charged the situation with a level of emotion that was bewildering to Marge and Earl and the members of the circle who had helped to create Sheri's living arrangements. They interpreted moments when either staff and housemates or Marge and Earl would "blow-up" as understandable reactions to the stress of living with Sheri, who became increasingly upset and withdrawn as the tide of emotion rose around her. The staff group, on the other hand interpreted both Sheri's upsets and their own occasional "blow-ups"

as inevitable consequences of Marge's over-controlling and manipulative behavior.

- There were neither words nor a forum to explore these differences. Since both the staff-housemate group on one hand and Marge and Earl and the other circle members on the other hand claimed the position of "knowing best", there was no space to build a shared understanding. After finishing the hard work of setting up Sheri's situation, a number of circle members had less reason to attend circle meetings and the circle's role and agenda became less clear. Though they attended meetings, and were considered members by Marge and Earl, staff saw the circle as the faction that supported Marge and did not invest themselves in making the circle a forum for surfacing differences. The extended the tactic of agreeing and ignoring to the circle.

As these interlocking forces grew stronger with time, Sheri lived in one house in which the people she relied on lived in two different worlds, worlds that spun farther apart each day.

Marge and Earl saw themselves as equal partners with the agency in innovation, creating a new way to offer assistance tailored to Sheri and Marge and Earl's unique situation. With the circle's support, they had carefully considered each element of Sheri's personalized service design in light of their own experience and the best information they could find from recognized experts. They expected bumps as staff learned how to implement the plan, and they were ready to lend their energy to smooth the way. They would not abandon staff, they would help out in practical ways: making the house more livable, managing Sheri's medical care, and filling in when there were gaps in the schedule. As the keepers of Sheri's dream and her history, they were confident that the staff would value their guidance. Because they had developed a way to support Sheri as an individual, they were sure that staff would appreciate being liberated from the problems of managing the needs of a group of people with disabilities. Because Sheri had a circle of support that included a variety of capable and knowledgeable and influential people, they believed that staff would feel supported and appreciate the backing the circle would provide in accessing resources they might need. Because Marge had spoken freely and at length about the family's hopes and expectations in the agency selection process, she was certain that they were all singing from the same page, even though anyone might from time to time be caught off-key.

Staff and agency management had a very different view based on a history of success in providing services. They saw service provider agencies existing for two purposes. First, to relieve families of the burden of caring for their adult children with severe disabilities. Second, to provide high quality programming to help each person to grow as much as possible while maintaining health and safety. These purposes define clear boundaries, which are necessary to the agency fulfilling its purposes. Staff and

the professionals who back them up have the expertise to design and deliver programs that meet a person's needs and satisfy the requirements of the systems that fund and regulate services. Competent guardians consent to placement, provide input to individual planning , and make decisions that their son or daughter are incompetent to make. Good parents maintain an appropriate relationship with their sons and daughters, respecting them as adults and taking account of the staff's role in their lives. When there are problems, guardians and parents resolve them through the agency's grievance procedures. Staff assist individuals with daily routines and personal development in line with the individual plan and manage households so that people will be healthy, safe, and, as much as possible, happy. Agencies make decisions about real estate and roommates and assist people to meet such obligations of tenancy as paying bills and dealing with landlords and neighbors.

These beliefs about the proper roles of agency and guardian form a consistent, common sense view of how and why work and responsibilities should be divided between them. This view seemed so obvious to the agency that it formed an unspoken background for their negotiations with Marge and Earl. Agency managers recognized that Marge and Earl intended to be more involved than most parents, but they saw this as a sign that Marge and Earl would need more time than most parents to develop trust in staff. They were confident that the skilled staff they recruited would satisfy Marge and Earl and thus facilitate their process of letting go of Sheri.

The agency managers saw themselves making a stretch into innovation by agreeing to test the feasibility of supporting Sheri as an individual and by trying the idea of community renters. They saw themselves as having the primary voice in deciding whether these arrangements were viable because they are responsible for contract compliance, for protecting employees by following labor standards and good human resources practices, and for dealing prudently with liability risks. They would test Sheri's personalized service design, they would evaluate its effectiveness taking account of feedback from family and staff, and they would modify it with Marge and Earl's input.

These two different understandings represented incompatible interests and relationships that came to be broken beyond much hope of repair. Efforts to improve the flow of information confirmed each side of the conflict in its perception. Staff realized that Marge and Earl had no intention of letting go of Sheri and following their retirement dream by taking long trips away. Marge and Earl realized that the agency could not continue to implement a service design that it did not believe was viable. The agency administrator, who had much less emotional investment than either staff or Marge and Earl did, was wise to call the question by withdrawing from the contract and wise to refuse to negotiate the alternative service design that the agency proposed as an arrangement it could sustain through time.

The importance and costs of individual funding

The first lesson of this difficult situation concerns the importance of individualized funding, an available variety of provider options, independent advice, and a clear separation between housing and assistance. Marge and Earl and the circle had the capacity to own the conflict with the agency and its results, to locate another provider and negotiate based on what they learned from their first year, and to redesign the way Sheri's assistance is managed without jeopardizing the essentials in her personalized service design. Sheri did not need to move. Sheri did not have to suddenly lose continuity with staff who wanted to continue to assist her. Sheri did not have to rely solely on the intervention of a case manager who may have had limited time to get to know her due to high caseloads and high turnover. If Sheri did not live in a region with multiple service providers, one of which was able and willing to take up Sheri's contract, Sheri and Marge and Earl's options would have been limited by their own ability to either take over management of all of Sheri's assistance or take her back home to live with them. If Sheri did not live in a region with staff willing to support innovative and individualized forms of support, Sherri and Marge and Earl would have had little bargaining power. If Sheri and Marge and Earl had not recruited and encouraged a circle that included a person knowledgeable and committed enough to be a skilled broker, the transition process would have been frightening and risky.

The second lesson accounts the cost of the first. Marge and Earl work to support Sheri and her circle. They had to absorb negative emotions from staff and housemates who they knew cared about Sheri but who came to resent and mistrust them. They had to face the uncertainty of finding a new agency and making a transition. They had to deal with others' honest doubts about the feasibility of the personalized service design that they had labored so hard to bring into being. They had to consider their own part in the conflict that threatened the security of Sheri's home. As many parents do, they found the strength to keep walking in their relationship with Sheri and with each other, in the support of circle members, and in the consolation of their religious faith.

The third and fourth lessons each take more explaining, so each has its own section below.

"Letting go" or "Growing into new relationships"?

For the third lesson, we have to reach farther, to see if the idea of differing ways to model "self" can shed light on the sources of the conflict. Briefly, we think that Marge and Earl acted in a way that emphasizes Sheri's relational self. Her self is formed by her changing relationships with those who invest in her and those she invest in. Her capacity to exercise control of her life depends on the active presence of people who see her as a whole and gifted person and who assist her in response to that vision of her. We think that the first staff group acted in a way that emphasizes Sheri's self as

separate. This separate self can only grow when she acts alone and takes individual responsibility for her actions. Sheri can never develop a self as long as her mother overshadows her.

We are reading this out of the situation that Sheri and Marge and Earl and the first staff group lived through. No one we interviewed talked about the conflict from this perspective. For all of them the conflict was something lived through more than something thought about at a distance.

To think about this situation as a conflict of differing views of self we have borrowed the lenses on human development shaped by members of the Stone Center at Wellesley College.[9] In a three point summary, this relational perspective says that: 1) people grow in, through, and towards relationship; 2) connection with others is central to well-being; disconnection and isolation inhibit development; and 3) throughout life people build growth producing relationships through mutual empathy, responsiveness, and contribution to the growth of each individual *and* the relationship. Jean Baker Miller and Irene Pierce Stiver summarize a key point of this understanding.

> *In our view, the goal of development is not forming a separated self or finding gratification, but something else altogether –the ability to participate actively in relationships that foster the well being of everyone involved. Our fundamental notions of who we are are not formed in the process of separation from others, but within the mutual interplay of relationships with others. In short, the goal is not for the individual to grow out of relationships, but to grow into them. As the relationships grow, so grows the individual. Participating in growth-fostering relationships is both the source and the goal of development.*[10]

This does not mean that people do not have individual experiences, rights, and responsibilities, though it is a thorough corrective to balance the over-emphasis on separated individuals common in North American culture.

When Sheri's first year staff and housemates told us about what they knew was best for Sheri and Marge and Earl, we heard them talking in terms of an implicit psychology of separation. Their model of normal development included the idea that people only grow when they separate themselves from their parents and act independent of their influence. Staff have an objective view of Sheri because they maintain appropriate emotional boundaries that keep them detached from her. Marge's involvement in Sheri's day-to-day life is pathological, an age inappropriate unwillingness to "let go" and give Sheri space to become a separate self –or as much of an independent self as her disability will allow. This over-involvement is motivated by Marge's inability to accept Sheri's disability due to unresolved grief and guilt. Earl, as nice a person as he is, enables Marge's enmeshment and thereby impairs his daughter's development.

[9] See J. Baker Miller and I. Pierce Stiver (1997). *The healing connection.* Boston: Beacon Press. J. Jordan, Ed. (1997). *Women's growth in diversity.* New York: Guilford Press. J. Jordan, Ed. (1991) *Women's growth in connection.* New York: Guilford Press.

[10] *The healing connection*, p. 22.

When Marge accepts Sheri's disability she will be able to turn Sheri over to staff who have a realistic understanding of Sheri's needs and can therefore assist her without becoming entangled. The clearest symptoms of Marge's problem are her unwillingness to observe the clear boundaries that should separate her from Sheri and her from agency staff and the irrational emotional responses she makes to issues that she believes affect Sheri's health.

Notice that this way of understanding does two things. It charts a course for normal development in terms of separation: people grow-up by growing out of and away from their family relationships. It also pathologizes Marge's relationship with Sheri, making what staff assume are Marge's unresolved psychological problems a cause of Sheri's difficulties and Sheri a victim of her mother's inappropriate involvement in her life. This sickness-seeking view invites a rejoinder in kind. Someone on Marge's side might say that staff –all women in Sheri's generation– identify with Sheri in order to work out unresolved guilt and anger toward their own parents. But dueling interpretations that seek to establish who is sicker than whom as the foundation for a claim to understand Sheri best and thus to be in charge of her daily routine could easily get out of hand in ways that would not benefit Sheri or anyone involved with her.

The relational model of self allows another way to understand. It marks as developmental challenges those times in people's lives that call for them to grow into new forms of relationship. Looked at this way, Sheri and Marge and Earl do face a challenge which may have painful and disorienting moments, but it is not the challenge of letting go of each other, it is a challenge of finding new ways to hold on to each other. The resources necessary to navigate into new relationships are the resources of growth fostering relationships: mutual empathy, responsiveness, and active concern for the growth of each of them and their relationship. Sheri's establishing her own home, while continuing to rely on Marge and Earl for regular practical support, provides a particularly challenging context for growth. They will need the support of all those who care for them as individuals and as a family to meet this challenge in ways that leaves each of them and all of them with more space to try new ways to relate to their world.

The problem of authority

The fourth lesson concerns authority. Advocates for self-determination stress the authority that these reforms grant people with disabilities or their guardians. Sheri and Marge and Earl's experience of Sheri's first year in her own home demonstrates that sufficient authority to define a personalized service design and choose and change service providers by no means settles the question of authority in day-to-day relationships between people with disabilities, their families, and the staff they rely on for essential assistance.

The problems of day–to-day authority disappear when everyone involved agrees that the choice of a service provider amounts to the choice of someone to assume the power delegated by the guardian and the state's regulations to control the person for their own good. However, Marge and Earl insist that they want staff who will enter growth fostering relationships with Sheri and those who care about Sheri. One element of these relationships is to follow Sheri's lead to the extent that all those who love and care about her can discern the path Sheri wants to take. Marge and Earl claim seniority in this process of discernment, not because of the legal authority of guardianship, but because they have the longest and closest relationship with Sheri and the most elaborated way of interpreting the body language through which she communicates.

In discovering Sheri's sense of direction, Marge and Earl don't presume to be able to translate Sheri with fluent accuracy. They often feel stumped by what Sheri may be trying to communicate. They are eager to think with staff and others who know Sheri about what she might mean, but Marge and Earl believe that others should carefully weigh their sense of what Sheri means.

Notice that this creates a hierarchy which structures discussions about Sheri in terms of who decides what Sheri means. This hierarchy scrambles the organizational boundaries that define the usual chain of supervision and control. By embracing the purpose of putting Sheri in the driver's seat of her own life, an agency either establishes Marge and Earl as authoritative in day-to-day matters or it must find ways and reasons to displace them. If Sheri's personalized service design depended less on the time and energy Marge and Earl give, this scrambling would only happen occasionally and could be dealt with through a process of periodic individual planning and consultation. But because they have almost daily contact and play the key role in the critical area of Sheri's health care, the question of how to deal with their understanding of Sheri endures.

This organizational dilemma clarifies the importance of a potentially growth fostering reciprocal of self-determination, which is deference. Deference means allowing someone else to take a higher place when there is uncertainty about what is happening or how to proceed. Deference doesn't mean abandoning one's voice or one's judgement or one's responsibility for one's own conduct. It means yielding to another's interpretation or judgement when there is no conflict between that person's judgement and one's own integrity. Deference does not mean standing aside and letting other's carry out their intentions. It means putting one's energy, skill, and knowledge to work within a direction set by another. Deference does not mean taking dictation from a superior being. It means joining in discussion, listening and questioning to clarify another's judgements and how best to respond to them. Deference does not mean sitting in passive silence while those above figure out what to do. It means sharing what one sees, feels, and thinks in the service of a common purpose. Deference

need not freeze people into static positions. When circumstances change the focus of problem solving, those who know most about what Sheri may be communicating defer to those who know more about the workings of the service system or the mysteries of wage and hour laws.

In Sheri's first year, staff and housemates acted as though a combination of being more like Sheri in terms of age and family position than Marge and Earl and holding a staff role should establish their authority and the reciprocal obligation on Marge and Earl to back away and let staff do their job as staff decided best. This resulted in the contorted communication and defective decision making structures sketched above.

For the past three years, Sheri's household has arranged itself on another principle of authority. Those involved with Sheri agree that their purpose is to assist Sheri in discovering and following her life's path. They further agree that Marge and Earl understand Sheri better than anyone else. As Sheri's best interpreters, Marge and Earl deserve deference when there is ambiguity about the best course of action, as long as their decisions don't violate others' integrity. In turn, Marge and Earl accept the importance of working in a team, listening and thoughtfully considering different ways to understand what is going on and what to do. "None of us is as smart as all of us", quotes Earl from a poster promoting teamwork.

In most discussions of self-determination, deference seems to hide in the shadows. Hierarchy is easily identified with domination and authority with authoritarian rule. The dangers of domination and authoritarianism are real enough, but not so much as to justify setting aside the resources of hierarchy and authority as important structures for necessary problem solving. Muddled authority threatened Sheri's security.

Deference is a difficult discipline in a culture that thinks mostly in individualistic terms, devaluing those who defer as though every relationship had to have winners and losers. Many people have a narrow zone within which they can defer without feeling offended. Entering a collaboration around Sheri offers opportunities to either widen one's zone of deference or decide that the work does not lie within one's gifts.

Back on track

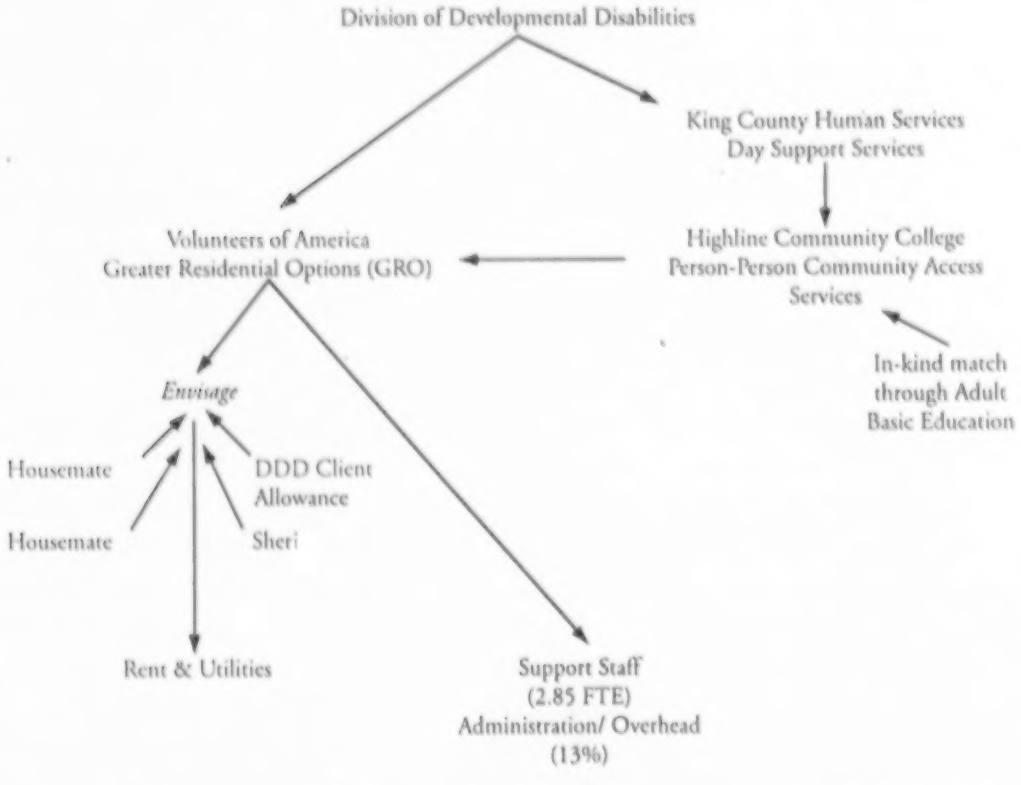
In the months following the change of provider agencies, Sheri's support team regenerated in a way that better expresses the realization that Sheri's self-determination depends on the state of the relationships around her. Both the staff and housemates in Sheri's first year and the staff and housemates that support her now could honestly say that they were concerned first and foremost with what was best for Sheri. The difference is that Sheri's current arrangements resolve conflicts in ways that strengthen, or at least do not threaten, the relationships Sheri counts on rather than polarizing her relational world into competing factions.

It might be tempting to think of this difference too simply, like this: at first Sheri was supported by misguided people who didn't listen to her, now Sheri is supported by good people who do listen to her. It seems both more respectful and more interesting to assume that both groups of good people listened to Sheri. They just listened from different places with different consequences for Sheri and her relationships with family, friends, and assistants. A new authority structure for decision making and a pattern of teamwork that strives to hold Sheri-in-relationship at its center has so far contained conflicts and difficulties in a way that has seen Sheri through an extended health crisis to a period of stable enjoyment of her home, her family and friends, and her neighborhood. No longer does Sheri vocalize her discomfort for hours at a time; now her vocalizations signal immediate difficulties which usually have immediate remedies.

New authority boundaries

As part of the transition to a new residential provider, a management group assumed responsibility for Sheri's support. Each member of the management group, including the representatives of the residential provider and the day service provider, are active members of Sheri's circle as a matter of personal choice. The management group meets regularly and, based on agreements between Marge and Earl and Sheri's residential and day services providers, holds the primary responsibility for problem solving and the authority to make decisions about staff job descriptions and compensation, hiring staff, selecting roommates, setting house rules and policies, making major schedule changes, and evaluating and modifying Sheri's personalized service design. The management group relies on GRO, the agency that holds Sheri's residential contract, for personnel and contract management. By agreement with Highline Community College, GRO manages Sheri's day service funds so that Sheri has a single, unified staff team. Karen, the director of Highline's community experience program and a long-time circle member, is a management group member, so are Duane, who is GRO's director and a circle member and Mary, a long time circle member and volunteer broker. Linda, Sheri's lead staff member, and Sheila, a staff member link the management group to the support team. Marge and Earl are active

in the management group and, because they provide day-to-day assistance to Sheri, they also play an active role in the staff team.



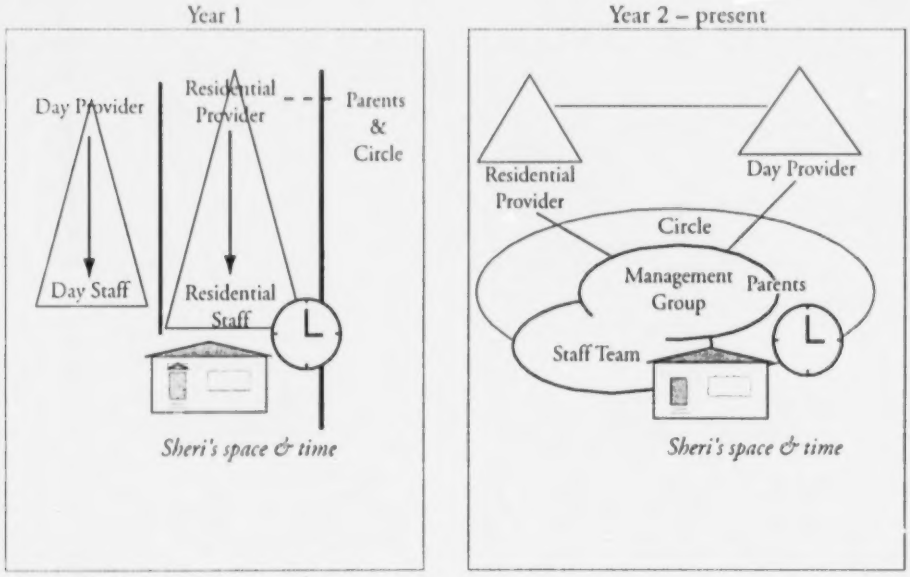
The management includes diverse voices: family, service contract holders, circle members, and Sheri's personal assistants. This allows a clear channel for each different interest to get the attention from the others that is necessary to do its part for Sheri. These diverse voices are unified by personal commitment to Sheri's well-being, appreciation of the central role Marge and Earl play in Sheri's life, and high personal expectations of one another.

Members of the management group are there primarily as people who care about Sheri, and secondarily as representatives of different interests. This puts the most potential strain on Duane. As both a member of Sheri's circle of support and the director of the agency that holds her residential services contract he could find himself in the middle if requirements on GRO diverged too much from what's necessary to implement Sheri's personalized service design. So far Duane and the management group have been able to negotiate organizational and service system demands without compromising Sheri's supports.

The only difficulty around Duane's role came when he proposed delegating his place on Sheri's management group to a subordinate manager with line responsibility for GRO homes in Sheri's area. The management group clarified its understanding

that membership is first a matter of personal commitment and only secondarily a matter of a person's role. Duane could delegate administrative duties; he could not pass on his relationship to Sheri and the management group. The trust in those key relationships grew from the thoughtful way Duane handled negotiations to take over Sheri's contract and from his personal contributions to the management group's work.

This diagram contrasts the decision-making boundaries around Sheri from the point of view of service providers. In the first year, service provider boundaries separated Marge and Earl and the circle from service providers, allowing for occasional parental input. A second boundary separated residential from day services. In a way Sheri's space and time are divided into segments and authority passes from one segment to the next depending on the time of day or the nature of a decision. As Sheri's support system has regenerated its boundaries, the circle contains all of the people who exercise day-to-day authority on Sheri's behalf, the management group forms a sort of umbrella over Sheri's space and time schedule.[11] This intentionally separates Sheri, her staff team, and her housemates from direct day-to-day accountability to any human service organization and locates decision making in Sheri's house, around her dining room table.



A new pattern of teamwork

With Marge and Earl's active participation, the first staff group were selected for training in communication with people with dual sensory impairments and experience in providing services. This staff group organized itself to teach Sheri to use manual sign and arranged classes to build skills for themselves and for other's who had regular contact with Sheri, especially Marge and Earl. As the difficulties outlined

Sheri's management group performs similar functions to a microboard. Microboards incorporate around the support needs of an individual, contract for funds, and direct the supports that a person gets. Microboards differ structurally from Sheri's management group, at least in that no one who is paid to provide services to the person can be a board member. For more information: www.microboard.org

above developed, the staff group bonded around blaming Marge for Sheri's troubles. Marge and Earl's non-standard ways of communicating with Sheri and their lack of investment in learning and consistently using standard manual sign became concrete examples of parental hindrance.

Sheri's current staff team grew differently. During the transition between agencies, Karen, a management team member who had known and worked with Sheri for years in the Community Access program, recruited Linda, a member of her staff who did not know Sheri, to work some evenings with Sheri. Karen felt that Linda's maturity, practical skill, and, most important, her passion for the work of assisting people with disabilities would benefit Sheri and help heal the hurts caused by months of conflict between staff and Marge and Earl. Karen's intuition has proven correct.

At first, Linda was struck by her own incompetence. She did not know sign and was unsure of her ability to understand Sheri well enough to assist her. She had not worked before with people whose parents were involved in their lives. It seemed to her that her presence only irritated Sheri. Linda expected other staff to provide training on how to communicate with and assist Sheri. "I wanted to get to know Sheri, but all my training was about how to handle Marge."

Duane, Linda, and Stafford

Through Sheri's angry vocalizing and physical resistance, Linda felt Sheri reaching out to her in a powerful way. In the staff group's preoccupation with Marge, Linda discerned three realities: the staff had failed to maintain focus on Sheri and Sheri was hurting because of this; Marge would be a very challenging person to work with; and, Marge was essential to Sheri. "I saw how Sheri changed when she was with Marge. Marge was Sheri's eyes and ears –everything but her breath. And I wanted to learn from Marge how to understand Sheri so Sheri would have more communication. I thought and prayed about it long and hard. I said to myself, 'OK, self. If you are going to do this you will have to open your heart and your spirit to Marge and to Sheri both. That will not be easy'"

Linda experienced Sheri, Marge, and the other staff relationally. She felt Sheri reaching out to connect with her. She wanted to share Marge's ability to communicate with Sheri in order to reduce both Marge and Sheri's isolation. She did not have a competing system of communication, she wanted first to learn Sheri's way of being with people. She recognized that staff worked to disconnect Marge and Sheri as a way to protect themselves from the challenge of dealing with Marge and Earl and she decided that if she were to respond to Sheri's invitation to be part of Sheri's life, she would have to open herself to the difficulties and the gifts that Marge brought. As she began to listen to Marge's story, "I saw a mother who was hurting for other people's rejection of her daughter's dream and potential. Marge has always spoken out boldly for Sheri and many other people have treated her as a threat and a pest."

Because she wanted the best possible relationship with Sheri, Linda deferred not to Marge as Sheri's guardian, but to Marge's relationship with Sheri as the relationship that best allowed Sheri to disclose herself. If Sheri is to discover and reveal more of who she is, it will be because different people join her life. Linda made herself a student of Sheri-Marge in order to build her own relationship with Sheri. Linda wants to add Sheri-Linda to Sheri's world and she does not believe it necessary to subtract from Sheri-Marge to do so.

Linda assists Sheri directly and leads the staff team. Linda's strengths do not lie in paperwork and she accepts Marge's tracking the flow of necessary paper as an aid in her assuring that Sheri's household and staff team run smoothly. Linda acts as what members of the circle have come to call "the balancing person." Life with Sheri, Marge and Earl is high in emotion and hurt feelings can distort the way people important to Sheri understand each other. Linda's bone deep concern to keep Sheri at the center of everyone's common effort grounds her role as balancer. One management group member who appreciates Linda's skill in holding people together observed, "If we didn't have Linda as a balancer, we'd probably have to employ a bouncer." When Linda herself feels out of balance, she counts on Mary or Karen to help her recover her center. Linda finds her Christian faith her deepest source of strength. That Marge and Earl share this faith with her strengthens the relationship among them.

Linda describes her leadership in terms of standing up for five ground rules:

- We are all here for Sheri and it is our obligation to hold her in the center of our concern.
- Sheri needs Marge and Earl.
- "Bring it to the table." When there is a conflict or a misunderstanding, everyone has a responsibility to avoid harboring bad feelings or gossiping about others and instead to bring the issue into the open.
- "Try hard to hear." Practice looking at situations from other's point of view. The only way to understand how a situation looks to someone else is to listen carefully to what they say.
- "Use your voice." Marge's often fierce concern for Sheri or her enthusiasm for new ideas can make it hard to speak up in a clear and thoughtful manner when one disagrees. Anxiety about Sheri's health can get in the way of thoughtful discussion too.

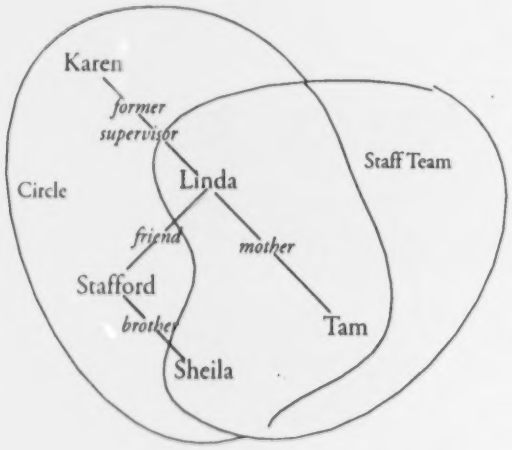
Sheri's team continued to grow as person-to-person recruiting complemented recruiting through ads in the paper.

Linda brought a new kind of energy into Sheri and Marge and Earl's life when she recruited her daughter, Tamla. Tam had no work experience with people with

disabilities but got interested when she met Sheri and saw Marge and Earl and Linda's relationships with her. "I saw them and I just knew I wanted to be part of Sheri's communication." Tam is younger than Sheri and spends 32 hours a week accompanying Sheri. When Sheri is well, accompanying her includes lots of activity. During the extended periods of Sheri's illness, it has often meant just sitting with Sheri when she lacks the energy to move around. Tam has taken turns with Marge and Linda spending nights with Sheri when she is ill.

Tam has been the source of a guiding image for the household team that includes both staff and Sheri, Marge and Earl. She sees them, and they have come to see themselves, as a multi-generational family of adults. This image suits the current reality. It unifies the people Sheri counts on day-to-day, underlining their shared commitment and common relationships. It makes room for their different positions and inevitable conflicts. Tam calls Earl "Poppa Earl" to describe his relationship to her and to whole the household group, but her respect for his position includes the expectation that he will deal openly and fairly with her as an independent person when the group disagrees. As Tam moves away to complete her degree, this unifying image may shift.

Tam and Sheri



Linda brought her friend Stafford into Sheri's life. Stafford has developed a commitment to help Sheri maintain a stable home. He also brought his sister, Sheila, to Sheri's team as a part time staff person.

Like Stafford, Sheila, an actress, had no experience of people with disabilities. She remembers her anxiety at meeting Sheri, her belief that once she had done her brother the favor of interviewing she would look elsewhere for a more suitable job, and the way Linda's relationship with Sheri changed things for her. "I couldn't stand drooling. I wouldn't even have anything to do with my baby nephew when he was drooling.

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And when I first sat down with Linda and Sheri and heard Sheri's noises and saw Sheri's movements I was sure I was in over my head. And then what happens but Sheri drools and Linda, without stopping her conversation with me, reaches over and casually wipes Sheri's mouth." Sheila calls this moment an epiphany, a moment of revelation that changed things for her. In that moment of sharing Linda's relationship with Sheri, Sheila glimpsed the possibility of a mutual relationship with Sheri. "If I had seen people who were distant from or somehow disgusted by Sheri, I would probably have had the same reaction. If I acted like Sheri was untouchable, then my family and my nephew probably wouldn't feel comfortable touching her. So I am grateful that. in my first moments with Sheri, Sheri and Linda were able to heal my disgust."

Sheila has come to appreciate Sheri as actively inviting Sheila into her life. Sheila has learned to synchronize herself with Sheri's body communication primarily by following Sheri's physical lead as they do everyday tasks together and by watching closely as Sheri interacts with others. Sheila and Sheri's relationship has grown closer as communication has grown better and their communication has grown better as their relationship has grown closer. "Marge passed me a picture of me and Sheri and I put it in my photo album. Sheri becomes part of my own family when her picture is in my album."

Sheila numbers Sheri among her teachers. "Sheri takes you out of the busy world of surfaces and into a world that is bigger than ever you thought it could be. Sheri gets you clear that inside, what counts is love and nothing else really matters."

Krishna works with Sheri on weekends. She came to the team in response to a newspaper ad that Marge wrote for GRO to place. Krishna came to Sheri because she wanted a weekend job that would provide the greatest possible contrast with her weekdays as a student film maker. The media world is organized around rapid pace, production, and relationships that come and go with the demands of projects. Before moving to Seattle for school, Krishna had worked for a family providing personal assistance to their disabled son, so she knew that such work offered her soul the balance she needed. This experience has also made it easy for her to fit into a team that defers to family preferences. In fact, she says that she did not know of another way to work with people with severe disabilities. Krishna's graduation project is a video that communicates Sheri's story.

Krishna and Sheri

The management group provides a clear, collaborative decision making structure that includes each of the voices Sheri needs to maintain and improve her personalized service design and forms a boarder between Sheri's household and the rest of the service system. The image of a multi-generational family of adults incorporates all of the people Sheri counts on day-to-day in a way that allows both a respectful

hierarchy and the room for each member to act and speak freely within the boundary of shared commitment to Sheri. The practice of building the core of the staff team based on people's ability and willingness to begin their relationships by modeling the relationships of others who know Sheri better has provided a flexible and definite rule of deference: when there are conflicts, people return to how they know Sheri, and, unless they feel their integrity at stake, when they cannot achieve consensus, Marge and Earl decide.

This combination of structures and rules has been robust enough to support Sheri in developing individual relationships with the different people who come to her. Each person involved with Sheri feels Sheri reaching out to them personally, inviting them into her life to play a particular part that benefits both of them. That this invitation and the relationship that develops from it happens beneath words does not seem to bother any of the participants. Sheri has been able to keep up her end in these relationships, and even reach out to form new ones, despite extended periods of ill health and very low energy.

Continuing uncertainties

Sheri counts on ordinary, fallible people to accompany her along a path that has often been difficult for her. Over the past three years, she has grown more comfortable and closer to a slowly growing number of different people who form a group who care for her and respect one another's commitment to her. However, she still relies almost completely on other people's interpretations of her spirit and her actions and her circumstances.

The fundamental ambiguity of Sheri's communication makes her a site of uncertainty among the people she counts on. Several uncertainties endure and raise differences among those who care about her, including these.

- Sheri's physical symptoms are difficult to evaluate. The doctors and other health practitioners involved with her have not been able to provide either a clear understanding of Sheri's health status or definitive treatments. People who care about Sheri differ about the effects of alternative health care treatments and prayer on Sheri's health.
- Sheri structures a lot of her time tapping hard objects on resonant surfaces, usually positioning herself so that she taps very close to her eyes and with her ear against or very close to the surface she taps on. Everyone agrees that this is a preference, but people differ about whether and how to invite her to get involved in something different when she "wants to tap." Some people think that Sheri's assistants might use her preference for tapping as a way to avoid the work of otherwise engaging her and Sheri might be tapping when she could participate more in household duties. Some people wonder if Sheri could be stuck in her tapping and missing other experiences that won't be hers unless the people around her increase their ability to facilitate her participation.

- Sheri has a few manual signs but those close to her feel that they have clear ways to communicate with her. People differ about the amount of effort Sheri and those close to her should put into systematically learning and using more signs or symbols. Some people think that Sheri could say more for herself and communicate directly with more people if her whole household used more standard communication.

These three areas of uncertainty and difference have been with Sheri at least since she moved into her home. They are reflected in the elements of her personalized service design. The first staff team pushed away from Marge and Earl and the circle over them. The second staff team has found ways to contain these uncertainties.

Looking to the future

Sheri has a secure base. More than twenty people have made the commitment to be part of Sheri's future by joining her circle. A capable and creative sub-group of the circle manages the implementation of a personalized support design that has proven its relevance for her well-being. Her household team has found ways to strengthen their relationships with her and deal with the inevitable conflicts that come up among them. Circle members have connections to resources that Sheri has not yet used.

As Sheri seems to be recovering her health and her energy, the attention of those who care about her turns to four questions about her future.

How can Sheri have more security in her home? As an innovator in her state's service system, Sheri relies on that system to keep making room for her as it re-designs itself in response to many demands. How can the circle assure that the system remains willing to support what Sheri and her allies have achieved? As a renter in a desirable neighborhood in one of the hottest real estate markets in the world, Sheri has relied on her landlords, a couple who live across the street, for a fair and affordable rent. What would it take for Sheri to own a home, perhaps even the home she now lives in?

How can Sheri contribute to her community as a volunteer or an employee? Marge thinks that Sheri should assume responsibility for a part-time paid or volunteer position. As Sheri's strength grows, those who care about her will be called on to learn how to develop the opportunity and the assistance she needs in order to work.

How can Sheri extend her ability to communicate even farther than she has until now?

What needs to be developed now in order to underwrite Sheri's security when Marge and Earl are no longer able to contribute as much as they do now to her daily life? Because of their primary role as Sheri's safeguard, this question implies a clear plan not only about estates and guardianship but about who will commit to advocating for Sheri. Because of the extent of their contribution to Sheri's everyday

assistance, this question also implies a plan for providing back-up, filling in for staff, managing Sheri's checking and medical care, and keeping the lawn mowed and the house in good repair.

As these questions testify, Sheri's walk toward self-determination continues to take her and those who chose to walk with her into new and frightening and exciting territory. Structural reforms, such as individual budgeting and independent brokerage, will help others to follow the path Sheri and Marge and Earl and their circle are breaking. Personalized service designs can offer people a good fit between the assistance they need and the lives they want to lead. But unless those Sheri counts on find effective ways to relate to one another as people whose shared work calls for a viable pattern of deference and authority, the barriers of moral conviction that keep people from imposing on others for their own good will be either too weak or too rigid to allow for life to flourish.